



A publication of the
New York State Association
for Bilingual Education

Journal of Multilingual Education Research

Volume 6 *Bilingual Special Education: Exploring
Pedagogical, Research, and Policy Implications*

Article 6

2015

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Recommended Citation

Ijalba, Elizabeth (2015) "Understanding parental engagement in Hispanic mothers of children with autism spectrum disorder: Application of a process-model of cultural competence," *Journal of Multilingual Education Research*: Vol. 6, Article 6.
Available at: <http://fordham.bepress.com/jmer/vol6/iss1/6>

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Understanding parental engagement in Hispanic mothers of children with autism spectrum disorder: Application of a process-model of cultural competence

Cover Page Footnote

Special thanks to the mothers for sharing their beliefs on disability and for participating in this study.

Understanding Parental Engagement in Hispanic Mothers of Children with Autism Spectrum Disorder: Application of a Process-model of Cultural Competence

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In this study the LEARN process-model of cultural competence was applied with three Hispanic immigrant mothers of children with autism spectrum disorder (ASD). Two main arguments were investigated: (a) The influence of cultural beliefs on mothers' engagement in their children's education at home, and (b) The inclusion of mothers' cultural beliefs about disability in education plans for their children. This study was contextualized through a review of the literature on cultural competence and traditional cultural beliefs on understanding disability in many Hispanic immigrant families. Results showed that mothers' parental beliefs about disability influenced how they engaged in their children's education. Their engagement was evident through life participation as opposed to academic involvement. The three mothers in this study ascribed their children's disability to cultural beliefs (*mal de viento* [wind sickness], *susto* [fright], and *mal de ojo* [hurtful gaze]). These cultural beliefs influenced how mothers engaged with their children and actively supported interventions for autism. Findings are discussed within frameworks of cultural competence, use of skilled dialogue, and ethnographic methodologies when working with culturally and linguistically diverse (CLD) families of children with special needs.

Keywords: special needs, disability, autism, immigrant families, cultural competence

Parents constitute a child's first and foremost influential teachers. As such, parents' engagement includes mediating language, literacy, and social cultural knowledge for their children (Bodrova & Leong, 2006; Ijalba, 2015; Vygotsky, 1978). Through predictable and often playful routines with their children, parents introduce the systematic use of words, turn taking, and shared attention to events in their daily life (Bruner, 1983). Because of parents' crucial role, we also know they can influence developmental outcomes for their children with language and autism spectrum disorders (e.g., Ijalba, 2015; Rodríguez-Brown, 2010; Walton & Ingersoll, 2015). In the case of culturally and linguistically diverse (CLD) parents and their children, there is a growing need to understand their cultural values, belief systems, and notions on

disability (Harlin & Rodríguez, 2009). Such factors can influence how parents understand development, autism, and their own engagement in their children's education and specialized interventions.

In this article, I consider parental engagement within frameworks of cultural competence. Broadly defined, cultural competence includes the behaviors, attitudes, and policies professionals need in order to work effectively across cultures (Cross, Brazon, Dennis, & Isaacs, 1989). The National Institutes of Health (NIH) describe cultural competence as *cultural respect*, indicating that professionals must build a body of knowledge, beliefs, and behaviors that facilitate the provision of services to CLD clients; that is professionals must be respectful of and responsive to the health beliefs, practices, and linguistic needs of diverse patients (NIH, 2015). Along the same lines, the National Education Association (NEA) emphasizes that teachers must build awareness of their own cultural identity, their views about difference, and that they should learn from the cultural and community norms from their students and families (NEA, 2015).

For young children with language and autism spectrum disorders (ASD), parental engagement rooted in family advocacy and cultural values establishes parents as critical partners with teachers in the education of their children (Ijalba, 2015; Rodríguez-Brown, 2010). Pivotaly, parental engagement encompasses how parents interact with their children to support social-emotional, language, and cognitive growth (e.g., Siller & Sigman, 2002). It also encompasses the ways in which parents communicate with school personnel and whether they are included as critical partners in their children's education (Harry, 2008). In order to become empowered and to serve as strong advocates for their children, CLD parents must build leadership skills, communicate their family needs to educators, and understand how to navigate educational institutions (Olivos, Jiménez-Castellanos, & Ochoa, 2011).

Notably, in order to achieve the goal of parents as critical partners in the education of their children, educators must establish frameworks of cultural competence to understand how CLD parents view disability, their expectations about development, and their notions about interventions for their children. Education planning that includes parents as critical partners is foundational to sound pedagogical practices. It is also critical to building social, cultural, and linguistic diversity within our school systems (e.g., García & Kleigfen, 2010; Lindsey & Lindsey, 2011; Olivos, Jiménez-Castellanos, & Ochoa, 2011).

Along with the transformative changes that must occur in empowering parents as critical partners, Hoover-Dempsey and Sandler (1997) propose three major constructs influencing parental engagement: (a) parental beliefs about their own roles, including the range of important and necessary activities parents can do on behalf of their children; (b) parental beliefs that their involvement is beneficial to their children; and (c) parental perceptions that the child and the school want parents to be involved. Among many other factors, these constructs can be heavily influenced by parents' cultural beliefs. Moreover, in the case of children with disabilities, the influence of parents' cultural beliefs can be exacerbated amidst the multiple social-emotional, educational and healthcare needs they must manage for their children.

In addition, cultural beliefs influence how parents understand their child's disability and ultimately determine their own involvement in education and specialized interventions. Maestas and Erickson (1992) found that CLD parents often ascribed their child's disability to external forces beyond their control (e.g., God, fate) and that their efforts would not bring about change in their child's development. More specifically, when parents believe that disability is the result of fate, illness, or supernatural forces, they can be swayed into submissive roles regarding educational interventions and access to care. In order to engage parents as critical partners in their children's education, it is crucial for school personnel to avoid deficit perspectives and to understand parents' cultural and traditional beliefs within frameworks of family-centered models of cultural competence.

Roadblocks to parental engagement can prevail when educators fail to work from a framework of cultural competence. For example, educators can perpetuate deficit perspectives for low-income and CLD families by describing them as lacking the knowledge to work with their children. In contrast, research studies consistently describe educated upper middle-class families as engaging in enriched language and literacy experiences with their children (Duursma & Pan, 2011; Lightfoot, 2004).

Conversely, the framework of *funds of knowledge* (Moll, 2015) rejects deficit views and advances parents' strengths in supporting their children's education. Using ethnographic research methods, Moll, Amanti, Neff, and González (1992) trained teachers to visit their students' homes and communities. The purpose was to gather information on students' families, including their social and labor history, which were part of the accumulated knowledge in each household. Such set of knowledge, specific skills, and social networks were described as the families' *funds of knowledge* (Moll, 2015; Moll et al., 1992). When teachers bring such information into the classroom and make it part of their curriculum, students' motivation for learning is enhanced and their academic outcomes improve. Such research demonstrates the importance of working from frameworks of cultural competence and integrating parents as critical partners in their children's education.

There is, however, a dearth of research on how to apply models of cultural competence with Hispanic immigrant families of children with ASD and other disabilities (Falicov, 2014). There is also an overall lack of research inclusive of CLD families in the area of autism, which may contribute to a late diagnosis of the disorder (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Zuckerman et al., 2014). In this article, I contribute to the literature by exploring cultural competence paradigms and by specifically focusing on the application of one of these models: LEARN (Listen-Explain-Acknowledge-Recommend-Negotiate) proposed by Berlin and Fowkes (1983). Even though this model originated in healthcare settings several years ago, its applicability can be particularly relevant today in home settings with CLD parents and their children with ASD (e.g., Westby, 2009).

Using a family-centered framework of cultural competence, in this study I consider disability from the perspective of three mothers of children with autism. As primary stakeholders (e.g., McWhinney, 1989) these mothers' cultural beliefs and values were explored in detail and considered within speech-language intervention

plans for their children. Thus, my aim in this article is to describe an individualized approach to education planning that is framed within each mother's cultural perspectives and views on disability. To contextualize this study, I first review the literature on frameworks of cultural competence and traditional beliefs among Hispanic groups.

Literature Review

Cultural Competence Paradigms and their Application in Working with Immigrant Families of Young Children with ASD

As mentioned earlier in the article, cultural competence refers to a broad set of guidelines that includes the behaviors, attitudes, and policies professionals need in order to work effectively across cultures (Cross, Brazon, Dennis, & Isaacs, 1989). An expanded form of this definition guides frameworks for the National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care (U.S. Department of Health and Human Services. Office of Minority Health [USDHHS], 2014). The National CLAS standards mandate the provision of "effective, equitable, understandable and respectful quality of services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs" (USDHHS, 2014, p. 1). When considering interactions with CLD families, constructs for building cultural competence share basic tenets derived from anthropologic, cross-cultural research, and their implementation in healthcare settings. A summary of these tenets, which are central to the process of building cultural competence include the following: (a) learning to appreciate other cultures and respecting caregivers' beliefs, particularly within the context of interventions; (b) developing awareness of one's own cultural biases and stereotypes, including the privilege of being in the role of provider; (c) recognizing the crucial role of caregivers in assessment and interventions; (d) eliciting caregivers' own explanations of how they understand the disability, including its causes and remediation; and (e) negotiating a common space where a mutually agreeable intervention plan can be implemented (Beach, Saha, & Cooper, 2006).

Closely related to the process of building cultural competence, the person-centered approach aims to view disability through the eyes of stakeholders (McWhinney, 1989). In the case of children with ASD, understanding the caregivers' perspectives is at the core of parental engagement. Westby (2009) integrates the person-centered approach with the professional's acquisition of cross-cultural knowledge and the building of cultural competence. Such paradigm involves face-to-face interactions between the client and professional, integration of the professional's intellectual knowledge, and learning from each other (client and professional) by listening to one another's stories. Face-to-face interactions or interviews facilitate learning and gathering information about caregivers' behaviors, values, and beliefs (Patton, 2015; Westby, 2009).

In addition, the use of *skilled dialogue* (Barrera, Corso, & Macpherson, 2003) can be useful in gaining knowledge about families during the interview process. Such knowledge or informed understanding of families and the culture has been described as building *anchored understanding* by using a variety of means, such as looking up

information and using ethnographic interviewing (Westby, 2009). Skilled dialogue (Barrera et al., 2003) involves utilizing the processes of *Respect*, *Reciprocity*, and *Responsiveness* when interacting with families. These three main processes involve: (a) *Respect*, including acceptance of the physical, emotional, and cognitive boundaries in people from other cultures when discussing disability; (b) *Reciprocity*, including recognition that both parties in an interaction can provide valuable contributions (i.e., interest in family stories and attention to the interviewer's communicative style are crucial in building reciprocity); and (c) *Responsiveness*, including putting aside the interviewer's preconceived notions, withholding judgment, and gaining true understanding of how caregivers' perspectives can influence their child's behavior.

Berlin and Fowkes (1983) incorporate premises of anchored understanding, skilled dialogue, and person-centered approach in their process-model of cultural competence in healthcare. In their guidelines, the acronym LEARN is used to assist providers in gathering information about children and their families. Each letter stands for specific steps in the process, which can be adapted and applied in special education: L (*Listen* to how caregivers conceive the cause and process of the disability; listen for healing strategies that are considered appropriate), E (*Explain* the provider's understanding on the disability, even if this is an educated guess), A (*Acknowledge* the caregiver's perspectives, find areas of agreement with the provider's understanding, and point out conflicts that can be resolved. An effort should be made to incorporate the caregivers' perspectives in their child's care), R (*Recommend* a treatment plan that is inclusive of both the caregiver's and the provider's views), N (*Negotiate* a treatment approach that is the product of a unique partnership in decision making between the caregiver and the provider. The purpose of the negotiation is to enlist the caregivers' engagement and true participation in the intervention process.)

In summary, the application of process-models of cultural competence in education involves recognizing and valuing the diverse cultural perspectives that caregivers bring to educational planning. Viewing disability through the eyes of stakeholders and applying strategies that ensure caregivers' active participation can be important steps in building parental engagement in their children's education and in specialized interventions, such as speech-language therapy. Such an approach is also crucial for educators and other professionals in building cultural competence when working with CLD families.

Traditional and Cultural Beliefs on Disability among Hispanic Immigrant Families

Accounting for 17% of the nation's total population, Hispanics are the largest growing minority in the United States (U.S. Department of Commerce, 2012). There are 5.1 million children of immigrant parents, constituting approximately 24% of all children in classrooms across the nation. Notwithstanding the use of Spanish as a shared language, Hispanics in the United States are a diverse multiethnic group, with varying levels of education, migration histories, acculturation, and socio-economic levels. Hispanics also share fundamental cultural values such as *familismo* and *personalismo* (Falicov, 2014; Valdes, 1996). *Familismo* refers to a collective sense of family support (Sabogal, 1987), which can influence shared-decisions regarding

interventions for children with disabilities. *Personalismo* describes the importance of friendly and warm interpersonal relationships as opposed to the formal relationships typically encountered in professional settings (Santiago-Rivera, Arredondo, & Gallardo-Cooper, 2002). Falicov (2005) describes concepts of extended family and traditional beliefs as resilience factors in the face of loss through migration. It is therefore important for providers to build close relationships with families, spend time building rapport and establishing *confianza* (trust), while acknowledging *respeto* (respect) for the nuclear and extended family (Falicov, 2014). Such cultural values can also influence parental engagement within intervention and educational contexts.

Among Hispanic immigrants, Mexicans constitute a majority (70%) and share not only the border, but also a long history with the United States. The next large Hispanic immigrant groups are from Dominican Republic and from Central America. These groups bring with them their own historical and cultural perspectives. For example, families from rural parts of Mexico, Ecuador, and Guatemala, often originate from communities with Indigenous roots and carry their own sets of traditional beliefs.

In Mexico and other Latin American and Caribbean cultures, the syncretism between Catholicism, Indigenous, and African beliefs gives rise to traditional healing practices, such as *curanderismo*, which refers to the spiritual and healing practices in some communities (Pereyra & Guzmán, 2010). A popular belief among caregivers from Latin American and Caribbean cultures is that of *mal de ojo* in young children. Pimentel (1998) described *mal de ojo* as the hurtful gaze of some individuals on young children. Among popular beliefs of the Quechua people, women who are pregnant are thought to have *sangre caliente* (very warm blood), and thus, an acutely strong gaze. Young children and the elderly must therefore avoid looking directly at pregnant women or risk being affected by *mal de ojo* (Castañeda, 2006). Among various Indigenous groups, when a person suffers *susto* (fright), the person's soul can leave the body, leading to mental problems. Razzouk, Nogueira, and Mari (2011) use the term culture-bound disorders to describe *susto* and *mal de ojo* as conditions reported in Latin America and often associated with depression. In their analysis of 140 studies, Razzouk et al. found that *susto* was often associated with emotional trauma or the witnessing of traumatic experiences lived by others.

Among Quechua belief systems, pregnant women must avoid exposure to winds, which are associated with the souls of the dead and possession of the mother or unborn child (Groenenwald, 2011). Hughes (2004) reports that among people living in the Andes, the phrase *mal de viento* (wind sickness) is commonly used to refer to problems experienced by expectant mothers during pregnancy or when giving birth.

Across the world, traditional belief systems influence how caregivers interpret and cope with disability and autism (Mandell & Novak, 2005). Divan, Vajaratkar, Desai, Strik-Lievers, and Patel (2012) described that in India most families of children with ASD consult their traditional systems of medicine, such as Ayurveda. In her study of South African families of children with ASD, Madlala (2012) described 80% first consult traditional healers and later try western doctors and professionals. Hughes (2004) reports that Indigenous women in Latin America prefer to visit traditional healers and do not trust medical doctors and related professionals. These findings suggest that

providers applying process-models of cultural competence must recognize the traditional beliefs held by caregivers when planning educational interventions.

In summary, process-models of cultural competence facilitate understanding the diverse cultural perspectives that caregivers bring to their children's education. Such understanding can provide important steps in building parental engagement among CLD families. I pose the following research questions in this study:

1. How do cultural beliefs influence mothers' engagement in their children's education?
2. How can I frame education goals for the children that are inclusive of the mothers' cultural beliefs about disability?

Methodology

Qualitative research methods are effective in understanding parental views on language development and disability (Damico & Simmons-Mackie, 2003; Hammer & Weiss, 2000; Ijalba, 2014; Kummerer, López-Reyna, & Hughes, 2007; Patton, 2015). Westby (2009) points out that it is not sufficient for educational providers to gain information about individuals only through assessment, observation, and consultation. Educators must increase their efforts to use ethnographic methods, such as interviewing members of the family and community who are familiar with the child. Interview methods based on the use of open-ended questions can serve to elicit valuable information (Patton; Seidman, 2006). Kvale (1996) provides guidelines in ethnographic (in-depth) interviewing that suggest beginning with open-ended questions and moving to a more narrow focus. This includes posing follow-up questions to initial open-ended questions; requesting examples for specific details; confirming information through direct questions; and completing the interview by using interpreting questions and checking with the interviewee.

In this study, I used qualitative research methods in the form of in-depth interviews to gain anchored understanding of the mothers' cultural beliefs about disability, their engagement in their children's education, and to reframe education goals within the context of family cultural beliefs. Life stories were generated (Patton, 2015; Seidman, 2006) and vignettes were selected for this study. I used the LEARN process-model of cultural competence (Berlin & Fowkes, 1983) to develop anchored understanding about each cultural context and the beliefs held by the mothers. In addition, I used skilled dialogue to promote respect, reciprocity, and responsiveness when interacting with each mother (Barrera et al., 2003). This approach helped me to develop speech-language intervention plans that were individualized and inclusive of the mothers' perspectives in a parent education program.

Participants

The three participants in this study were Hispanic immigrant mothers (Mean age 30, *SD* 2.08) of children diagnosed with ASD who were enrolled in special education programs. The mothers were recruited at a special-needs preschool through letters that were sent home inviting them to participate in a parent education research study. The mothers signed informed consent and agreed to participate in the study. One mother was from Ecuador; one was from Mexico; and one was from Dominican

Republic. Their average number of years of education was 6 (*SD* 4). They lived in the United States for an average of 14 (*SD* 6.02) years and they were residents of New York City. They were only proficient in Spanish. They reported income levels below the poverty threshold of \$23,400 for a family of 4.

The children were two boys and one girl diagnosed with ASD. They had received bilingual speech-language evaluations and psychological assessments. They ranged in age from 3.5 to 5.6 years. The children scored within the severe range of autism on the Children's Autism Rating Scale (CARS; Schopler, Van Bourgondien, Wellman, & Love, 2010). Their communication skills were limited and ranged from lack of expressive vocabulary to the use of single words within context. The children used few gestures such as pointing to express their needs. They had commensurate problems in language comprehension, such as responding to their name when called or difficulty in following simple verbal commands. They also had difficulty with joint attention or their ability to look at objects during shared activities. The children presented stereotypic vocalizations and repetitive behaviors that further interfered with their ability to communicate and relate in their social settings.

Procedures

I am a bilingual speech-language pathologist and native Spanish-speaker from Uruguay. I shared this personal information with the mothers in this study to show that I identified as a Latin American, who shared many cultural beliefs with them. I met three times individually for weekly in-depth interviews with each mother. Each interview lasted between 60 to 90 minutes. All interviews were conducted at the school in a room free of distractions. The interviews were conducted in Spanish, audio-recorded, and transcribed verbatim. Brief excerpts from these interviews are presented in the Results section in this paper.

Instruments

- LEARN process-model of cultural competence (Berlin & Fowkes, 1983) was used to guide interactions with the mothers. The LEARN process model is described earlier in the article.
- An author adapted Question Guide (Kvale, 1996) was used during the in-depth interviews. The questions follow an open-ended to narrow format. The purpose of these questions was to obtain specific information about the mothers' cultural beliefs, views on disability, engagement in their children's education, and about each child's development. See Appendix for the Adapted Question Guide.

Results

Cultural Perspectives on the Causes of Autism: *Mal de viento, Susto, and Mal de ojo*

The participating mothers in this study had many unanswered questions about their children's social behavior and problems with communication. Each mother's emotional experiences during pregnancy, their traditions, and cultural beliefs influenced how they interpreted autism. In trying to find answers, mothers expressed preoccupation about conditions during pregnancy that could explain their children's

problems. From these mothers' perspectives, autism was caused by external factors that affected their pregnancy or their young child after birth. Three conditions are presented and contextualized within the LEARN process-model: (a) the Quechua traditional belief of *mal de viento* (*wind sickness*); (b) the Latin American folk belief of *susto* (*fright*); and (c) the Latin American folk belief of *mal de ojo* (*hurtful gaze*). In the following sections, all participants' names are pseudonyms (Erminia, Veronica, and Demaris).

Mal de viento—Traditional Quechua belief. Erminia, originated from a Quechua indigenous community in Ecuador. Her village was located in the “sierra” (Andes mountains) with less than 200 inhabitants. Her husband migrated to the United States when she was pregnant with her first child. Two years later, she crossed the border from Mexico to the United States to be with her husband. Erminia left her two-year old daughter with the girl’s grandparents, hoping to return within one year. When her son Juan was born in the United States, Erminia did not return to Ecuador within the year, as she had planned. In addition, Juan did not develop as expected and he was diagnosed with autism when he was 3.7 years old. Erminia then knew that she could not return to Ecuador, as there were no services to treat autism in her village. This lengthy separation from her daughter caused her great sadness, to the point that she often cried and could not interact well with Juan. In addition, Erminia believed that Juan’s autism was due to a frightful experience she had when exposed to a cold wind during her pregnancy. For Erminia, finding a “cure” for autism meant sending her son Juan to Ecuador to be seen by their village *shaman*, or healer. Since neither Erminia nor her husband had legal residency in the United States, Juan had to be sent in the care of the airline. This was a difficult decision, which was influenced by their family in Ecuador who wanted Juan to visit. Even though Juan, at the age of 5.6 years had limited receptive-expressive language skills or understanding of the situation, the family (parents and extended family in Ecuador) decided that Juan would travel for a one-month visit during the summer. The following excerpt describes how Erminia understood autism within the context of her frightful experience while pregnant, and how she came to the decision of sending Juan to Ecuador.

Un día yo iba caminando ya cerca de mi casa y una sombra, como aire frío se cruzó en frente en mi camino... yo no sé que fue pero sentí mucho frío y eché a correr hasta la casa... después ya siempre sentí dolor en el vientre...Yo creo por eso Juan nació así con esos problemas... allá en mi pueblo hay un señor que sabe de esas cosas... y por eso lo mandé al Juan... y también para que su hermana y sus tíos estuvieran con él...todos le querían ver y dijeron que le mandara... Ya después que el señor que sabe lo ha visto me han dicho que hay que esperar...es difícil de sacar lo que tiene... pero que va a estar mejor... yo lo veo mejor...ya está hablando más. [One day I was walking close to my house and a shadow, like cold air crossed in front in my path... I do not know what it was but I felt very cold and I ran all the way home... later I always felt pain in my belly... I think that is why Juan was born with all those problems... there in my village there is a knowledgeable man who knows about those things... and that is why I sent Juan... and also so that his sister and uncles could be with him... they all wanted to see him and they told me to send him... After the man who knows saw him I

was told to wait... it is difficult to take out what he has... but he will be better... I see him better... he is already speaking more.]

Analysis: Cultural context. In the Quechua belief systems the duality of hot and cold is associated with life and death: the human body is hot and the souls of the dead are cold. These two reside in parallel systems and should not meet (Groenenwald, 2011). The Quechua believe that when there is a disruption in the environment, spirits can cross into the world of humans and create havoc (Castañeda, 2006). Pregnant women are particularly susceptible to these encounters and they should avoid leaving their home. If a woman encounters cold wind or *mal de viento*, this force can enter her body and her child can be born with problems or even aborted (Groenenwald, 2011). Erminia's explanatory model for her frightful experience with the cold wind was as follows:

Pregnant → Should stay home → Ignored customs and walked outside → Cold wind → Pain in her belly → Autism

Analysis: LEARN process-model. Listening and finding common ground: I used my expertise as a speech-language pathologist to praise Erminia for being such a strong mother and for doing her best to keep her family together. Subsequently, I explained that sometimes mothers of children with autism need support to overcome feelings of sadness and depression. As a speech-language pathologist, I then explained about autism by using language that was free of professional jargon to make it more accessible to Erminia. I also stressed the importance of establishing consistent social interactions to stimulate language for Juan. I acknowledged the belief about cold and hot elements held by the Quechua people. Aware of the importance of *personalismo* and of building *confianza*, I disclosed that when growing up, I was not allowed to dip in cold water after eating, because digestion was considered to be a "hot" process and could be disrupted by the cold water. I inquired if such a belief was part of Erminia's cultural traditions. Since Juan had sensory issues, I went on to recommend using sensory activities involving temperature to stimulate language, increase use of his hands and expand eating preferences. For example, Erminia and I discussed making homemade play-doh and placing it in the refrigerator before molding it during play with Juan. Erminia also suggested making hot chocolate, preparing ice-pops, and making tortillas. I recommended providing visual supports in the form of experiential books for each activity. These books would be prepared with pictures about the objects and include steps for each activity. Such books would serve as augmentative communication to facilitate comprehension for spoken language and would also stimulate language and literacy. Erminia then went on to discuss the importance of maintaining close emotional ties with her daughter and relatives in Ecuador. Because family separation was one of Erminia's main concerns, the theme of family unity was used to negotiate treatment. Erminia and the author looked at family pictures where Juan smiled and seemed happy with his older sister, grandparents, uncles, and cousins. Together, we decided to print pictures and to create an album with simple social stories about Juan's experiences with his family. To conclude, I commended Erminia for her brave decision to send Juan to see his extended family during the summer and to be cured by their traditional healer. However, I also stressed that in order for the healer's "cure" to work

for Juan, it would be important to now follow up with the current activities and treatment plans at home.

Susto—Latin American folk belief. Veronica was a mother from Mexico who was brought by her parents to the United States at the age of 5. Her family members were migrant farm workers and followed the harvesting of tomatoes in the south of the United States. Because they were constantly moving, Veronica only received formal schooling through the first grade. She taught herself to read and write in Spanish, however, she did not feel confident about her literacy skills. Veronica never learned to speak English, even though she lived most of her life in the United States. She described having a very difficult childhood and always being unhappy at home. She met the father of her children when she was 14 years old, they eloped, and they have been together for over 15 years. Because of her limited schooling, Veronica described feeling unprepared to engage in literacy activities with her child Alex, who was diagnosed with autism. She explained that Alex used words until the age of 18 months and then suddenly stopped talking. Veronica believed he was frightened by something he saw through a window one evening, when they were together. Veronica could never find out what Alex saw, but she always lowered her voice when describing that event. When Alex turned 26 months and he was still not talking, she alerted his pediatrician and Alex was referred to early intervention. At that time, Veronica described living in a shared basement apartment, where the other tenants rejected Alex. They called him “loco” and did not allow him to be in common areas, such as the living room or the kitchen. Veronica and Alex only left their room during weekdays, when the other tenants were working. They stayed locked in their bedroom most of the time during weekends. This is how Veronica described the experience of *susto* that she believed Alex had and which led to his diagnosis of autism:

Alex estaba conmigo... y yo le estaba hablando, tenía como 18 meses...de pronto se volteó hacia la ventana y miró algo...se tapó los ojos y comenzó a llorar y ya no paraba de llorar...después se fue a dormir y estaba inquieto y al otro día cuando despertó ya no habló mas...yo no sé que pudo ver que lo asustó y lo dejó enfermito. [He was with me...and I was talking with him...he was about 18 months...suddenly, he turned to the window and saw something... he covered his eyes and cried and would not stop...then he went to sleep and he was restless and when he woke up the next day he did not talk anymore...I don't know what he could have seen that scared him and left him sick.]

Analysis: Cultural context. *Susto* is a folk belief reported by individuals across Latin America. It is described as a fright episode due to an unexplained event or simply by being startled. Children and women are particularly prone to *susto* (Castañeda, 2006). The medical literature associates *susto* within the category of post-traumatic stress disorders (Razzouk et al., 2011). In the case of Veronica and her son Alex, there was a history of stressful living conditions that were difficult. As the mother of a child with autism, Veronica could not find respite at home and she had limited sources of social support. As someone with limited education and unable to communicate in English, she did not have access to information about autism and she could not understand why her son had difficulty acquiring language and with other social behaviors. This mother's explanatory model for the role of *susto* was as follows:

Looks out the window → Sees something frightening → Susto → Crying, restless sleep → Stopped talking → Autism

Analysis: LEARN process-model. Listening and finding common ground: As a speech-language pathologist, I first praised Veronica for taking care of her child so well and in spite of their difficult household circumstances. I then explained that children with autism often forget or stop using some of the words they know or previously using. Having knowledge of Latin American cultural beliefs, I acknowledged familiarity with Veronica's belief in *susto*. I then went on to discuss the importance of a calm and soothing home environment for young children. Veronica commented that she avoided playing anything with violence on television, even cartoons, where there was fighting involved. She also maintained a very soft and calm voice in her interactions with Alex. Veronica described using television in English to teach Alex, since she was unable to communicate in English. I explained that using Spanish with Alex would be beneficial and he was likely to learn English faster when learning Spanish. I also discussed the importance of maintaining consistent reciprocal social and verbal interactions between Veronica and Alex to stimulate language. I advised Veronica to limit television viewing and to engage Alex in shared play and literacy activities. Veronica had concerns that Alex frequently cried or threw tantrums when he wanted things. This led to recommendations about language enrichment activities within the home context, alternative and augmentative ways of communication if Alex was not using words, and exploring whether Alex might be using crying to communicate his needs. Veronica and I then decided on a negotiated plan to introduce visual supports that would allow Alex to request for his favorite foods and toys by pointing to pictures. I provided interactive literacy activities with laminated pictures for target concepts. These brief interactive picture books had limited but repetitive printed text in Spanish, therefore Veronica felt comfortable reading them daily with Alex. To encourage peaceful sleep and to avoid *susto*, we also discussed bedtime routines and the use of visual schedules. I also encouraged Veronica to check with her family elders and with folk specialists who knew about additional ways to prevent and to cure *susto*.

Mal de ojo—Latin American folk belief. Demaris was a mother from the Dominican Republic. She migrated with her family at the age of 14 and was placed in the 9th grade based on her age. However, in the Dominican Republic, Demaris had only completed through the 5th grade. Her reading and writing skills in Spanish were limited. She was placed in a bilingual class during the 9th grade and transitioned to an English class in the 10th grade. She described not understanding what was being taught and she soon refused to go to class and dropped out of high school. This led to many problems with her family and she soon ran away from home. Demaris's relationship with her parents remained difficult through the years and they were not a source of support in her life. She had problems with depression and substance abuse. She met the father of her daughter when she was 21. He was from El Salvador and he did not have legal residence in the United States. He was deported when Jenny was 18 months old. Unable to pay for rent, Demaris then lost her apartment and lived in a shelter for over a year. Her daughter Jenny was a very pretty girl, who easily smiled but did not communicate verbally or through gestures at the age of 38 months. Her language comprehension was also very limited and she needed guidance for most simple

routines. Demaris described that Jenny used to say several words prior to the age of 24 months. However, according to Demaris, her daughter stopped talking after a woman resident in the shelter, expressed envy when gazing at Jenny. Demaris was convinced her daughter Jenny was not talking because she was suffering from *mal de ojo*, (hurtful gaze) a belief that is popular in the Dominican Republic. Because of this fear, Demaris did not want to leave Jenny with strangers (teachers at the preschool) and she often kept her at home. Demaris said she knew a “señora” or healer, who could remove *mal de ojo* by means of a special massage. Demaris also placed an amulet on Jenny. This is what she said:

Es que vea... Jenny es muy linda...es como una princesa... tiene ese pelo tan hermoso que todos me la miran... ella antes hablaba y miraba libros... pero hay mujeres que tienen envidia...me la miraron y ya despues dejó de hablar...por eso yo no la deajo sola...y es que a mi nadie me ayuda...yo me arreglo con todo...esta manito es para protección. [Look...Jenny is very pretty...she has that beautiful hair that everyone looks at her... she used to talk and look at books ... but there are women with envy...they looked at her and then she stopped talking ...that is why I do not leave her alone...and no one helps me...I take care of everything...this little hand protects her.]

Analysis: Cultural context. *Mal de ojo* is a widely spread folk belief in Latin America and the Caribbean (Pimentel, 1998). Very young children are believed to be especially susceptible to *mal de ojo*. It is therefore inappropriate in some Latin American contexts for strangers to approach young children and to praise how beautiful they are. Mothers often protect their infants and young children with amulets and keep close watch over them (Pimentel, 1998). Among some Indigenous groups, pregnant women are believed to have a strong gaze that can make children ill (Castañeda, 2006). In the medical literature, individuals who report *mal de ojo* are described as having a higher incidence of depression and of having witnessed trauma (Razzouk et al., 2011). In Demaris’s case, she reveals a difficult history of losing her child’s father to deportation and later having to live in a shelter, both traumatic situations. She believed that Jenny’s problems originated with people she did not trust at the shelter. Demaris’ explanatory model for the role of *mal de ojo* was as follows: Child is pretty → uses spoken words, smart, likes books → stranger looked at her with envy → *mal de ojo* → stopped talking → Autism

Analysis: LEARN process-model. Listening and finding common ground: As a speech-language pathologist, I praised Demaris for taking care of Jenny so well. Subsequently, I explained in language that was free of professional jargon that children with autism tend to have difficulty with language development and sometimes stop using words. I was aware of the *mal de ojo* belief and acknowledged it was held in many parts of Latin America. I then went on explain that regular attendance to school would be important for Jenny to develop language and social interactions. Demaris stated that Jenny enjoyed looking at books and this was their favorite activity together. I then recommended interactive reading activities in the home language Spanish, to promote joint attention and focused stimulation for target concepts, and to increase caregiver-child interactions. We again discussed the importance of sending Jenny to school.

Demaris and I negotiated a treatment that would include the use of interactive picture books in Spanish using Jenny's preferred themes, such as dressing like a princess, playing with bubbles, bathing, and birthday parties. I also encouraged Demaris to follow up with the "señora" or folk specialist on ways to cure and to avoid *mal de ojo* from recurring.

Discussion

Parents' cultural beliefs associated with health and disabilities are often ignored in the planning and implementation of interventions for children with language and autism spectrum disorders (Mandell & Novak, 2005). There is a growing need for research on how CLD families understand autism and the developmental challenges faced by their children (Harlin & Rodríguez, 2009). For the mothers in this study, parental beliefs about disability strongly influenced how they engaged and participated in their children's education. The three mothers in this study made decisions based on their cultural beliefs that impacted their children's learning contexts and experiences at home.

Hoover-Dempsey and Sandler (1997) proposed that parental engagement in children's education is determined by how parents perceive their role and the range of important and necessary activities for their children. The three mothers in this study felt an urgency to protect their children from unknown forces that could hurt them. The unexpected harm that could come to their children was evident in each of their life stories. Razzouk et al. (2011) documented the higher incidence of depression and traumatic events among Latin American individuals who reported *susto* and *mal de ojo*. The mothers in this study shared difficult life histories that included family separation, economic hardship, difficulty accessing education, and lack of social support. The literature reveals their difficult life stories are not unusual within the context of immigration (e.g., Yoshikawa, 2011). Immigrant families must frequently endure separation from loved ones, deportation, living in poverty, reduced access to healthcare, and limited employment and education opportunities (Flores & Tomany-Korman, 2008; Hernández & Naperiala, 2012; Passel & Cohn, 2011; Yoshikawa, 2011). For the mothers in this study, their cultural beliefs about disability and their actions to protect their children count as resilience factors in the face of adversity (Falicov, 2005, 2014).

Notwithstanding, these mothers' actions diverged from school-centered efforts to improve developmental and academic outcomes for their children. For example, Erminia did not send her child to a school summer program, but sent him abroad to visit family and a shaman; Veronica relied on providing a calm environment and using television to teach English to her child; and Demaris often kept her daughter in a protective environment at home, rather than sending her to school. In spite of their lack of convergence with school-centered educational perspectives, these mothers believed their actions were beneficial to their children and in that sense, they showed parental engagement. Rather than through academic involvement, these mothers' engagement was evident through life participation—their shared activities in everyday living, which is consistent with observations by Zarate (2007). Ingram, Wolfe, and Lieberman (2007) stress the importance of building parent capacity by encouraging

learning-at-home activities with CLD families. Such an approach may be particularly important for children with ASD and other disabilities.

Process-models of cultural competence can bridge differences between the school and family perspectives on education. Anchored understanding about the cultural context allows providers to frame parental perceptions on disability within a socio-historical context. Religious and folk beliefs must be contemplated within that socio-historical frame of reference. Maestas and Erickson (1992) found that when parents ascribe their child's disability to external forces beyond their control, they often feel ineffectual in bringing about change in their children's development. Other researchers report similar findings regarding views on disability in CLD families (Mandell & Novak, 2005; Rodríguez & Olswang, 2003). For the mothers in this study, the situation was more complicated. Each mother exerted control, even if it diverged from the school-centered approach. The three mothers in this study were proactive in making decisions they thought could benefit their children.

In this study, I used skilled dialogue (Barrera et al., 2003) to facilitate the mothers' engagement as partners in developing plans for their children's intervention. Respect for the mothers' beliefs and boundaries, reciprocity in recognizing their contributions, and responsiveness in gaining understanding were essential aspects that I maintained in the application of the LEARN process-model (Berlin & Fowkes, 1983) of cultural competence in this study. In particular, I negotiated interventions that included the mothers' perspectives in addition to the professional recommendations. Such an approach steered me away from dualistic interpretations and toward what Barrera et al. (2003) described as a third space in delivering culturally and linguistically appropriate interventions.

Conclusions and Implications for Further Research

Several aspects are essential in building cultural competence when working with CLD families. The use of ethnographic interviewing can facilitate in-depth understanding of each family's circumstances (Kvale, 1996; Westby, 2009). Incorporating a person-centered approach can allow professionals to view disability through the eyes of the stakeholders (McWhinney, 1989). Learning about each family's funds of knowledge can be used to generate interventions inclusive of caregivers' expertise and within the framework of family ecology (Moll, 2015). Understanding how families incorporate resilience in the face of adversity steers away from deficit views about caregivers. Taking into account cultural differences in social interactions such as *personalismo* and the building of *confianza* can improve rapport and sustained parental engagement when working with Hispanic families (Falicov, 2014; Santiago-Rivera, et al., 2002). To conclude, building cultural competence is an ongoing and dynamic process, one that draws from several competencies among professionals working with CLD families and their children.

In presenting these three case studies, I aimed to demonstrate the relevance of using a cultural-process model such as LEARN and its supporting frameworks such as anchored understanding and use of skilled dialogue when working with culturally and linguistically diverse families. Further research is needed to demonstrate the efficacy of

this model and its supporting frameworks, its adaptability in education, and its implications for parents and their children.

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Acknowledgements

Special thanks to the mothers for sharing their beliefs on disability and for participating in this study.

Appendix

Adapted Question Guide for in-depth interviews

(8 steps adapted from Kvale, 1996)

1. Introducing the questions

Tell me about your child. Tell me about your family.

2. Follow up questions

Why do you feel that way? What worries you?

3. Probing questions

Can you tell me more about that? Do you have an example?

4. Direct questions

Tell me, what are your child's difficulties? What do you know?

5. Indirect questions

What do you think could help your child?

6. Maintaining structure

Break up long responses that are off topic

7. Silence

Allow pauses for reflection. Let the interviewee break the silence by adding information.

8. Interpreting questions

So you think that...